



HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

2021 Annual Report



SUPPORT, EDUCATE, EMPOWER



Commitment to Our Mission

The Huntington's Disease Youth Organization is an international non-profit supporting, educating, and empowering young people up to 35 years, impacted by Huntington's Disease (HD).

Our aim is to provide a safe place to **support, educate & empower** young people & their families. We do this through several online and in-person resources.

Who We Help:

HD impacts far more people than just those who have the disease. Impacted for us includes -

- At risk for HD
- Young person gene tested with a positive or negative result
- Diagnosed with HD or JoHD
- Those not at risk who have family, loved ones, friends with HD
- Caregivers who may/may not be at risk
- People who know someone with HD
- Learning about HD for educational purposes
- Feeling concerned about HD for any reason

HDYO.org – The center of our support & education.
14 languages & huge range of content for different ages.
Nov 2021, we launched our new redesigned website with the new branding & enhanced navigation.
Direct support is provided by our staff.

Educational Programs

JOIN-HD: The Juvenile-Onset Initiative for Huntington's Disease - A Global Registry to connect the community of those affected by JOHD, increasing the understanding of the disease & encouraging future research.

HDYO International Congress - A program of insightful talks, sharing, research updates, peer support & fun!

Youth Mentorship Program in Partnership with HDSA - This program provides a young person (mentee) with one-on-one time with another person (mentor) who will receive training, & ongoing support

International Ambassadors - Young people who bring real-life experiences to better advocate for the entire community.

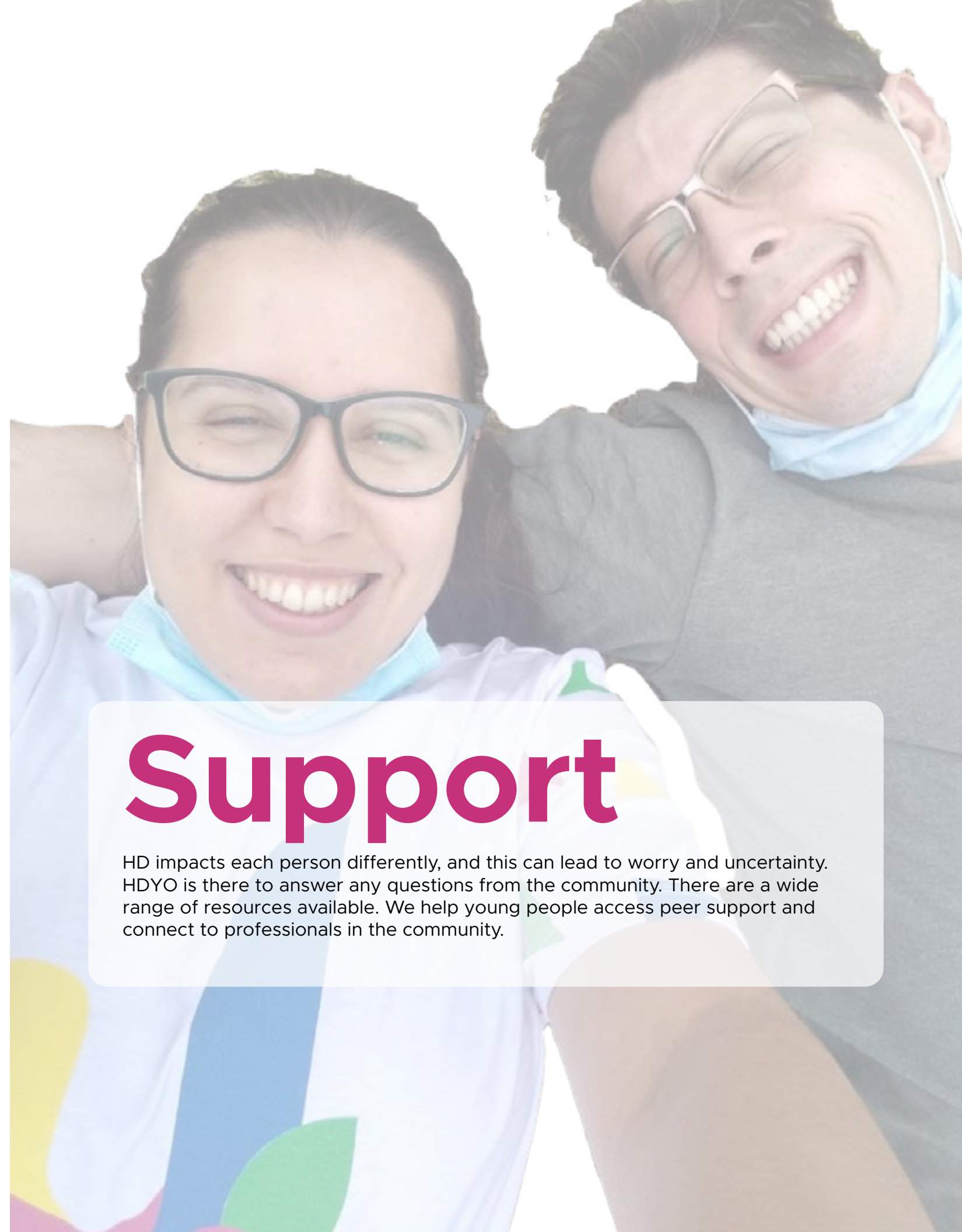
Research Video Series - In partnership with HD Buzz, we develop frequent videos to showcase the latest news in HD research.

Breaking Down Barriers Series - We tackle the stigmas surrounding HD

HDYou Community Stories - Featured interviews with members of the HD community.

Support

HD impacts each person differently, and this can lead to worry and uncertainty. HDYO is there to answer any questions from the community. There are a wide range of resources available. We help young people access peer support and connect to professionals in the community.



SUPPORT

Enhanced Website Navigation & Support

Since HDYO.org was launched, it has provided essential support and education to more than 7 million people across the globe. In 2021, we launched our new updated more engaging visual identity; brighter colors and updated logo. This was implemented on social media first then rolled out across all materials. We then launched our new redesigned website using our new impactful branding. We also took the opportunity to revise the structure, the menus, the tiles and the administrative side to allow for continual content updates. These updates are more welcoming and easier to use for the broad range of young people who need support and resources.

There's still the same great content to help each age group, and we've continued to review articles to ensure they represent the latest in HD needs.

Asking for help, support or advice is also a main focus on HDYO.org as many people need immediate assistance. Our team is here to help!



From the Community

Thank you! It's all thanks to you and your help. I will always pray for you because I was living the most difficult days of my life from anxiety, depression, crying and sleep deprivation. When I talked to you, my life changed, rather it was complete, and I had hope! Young person

Youth Mentorship/Mentee Program

In partnership with the HDSA, the mentorship program is designed to support young people across the United States who face the everyday challenges of growing up in a family affected by HD. This program provides youth (mentee) with one-on-one time with another person (mentor) who will receive training, and ongoing support from a Youth Social Worker within the HDSA. We are actively accepting applications for mentors and mentees to expand this program future after our pilot.

In Partnership With



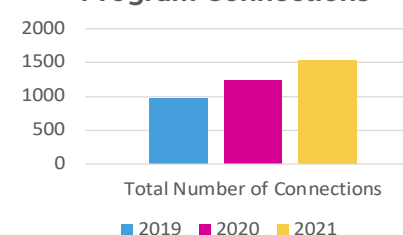
Being a basic science HD researcher with some clinical experience, helped me understand the background of the disease and the impact it can have on thousands of HD families. HDYO and the mentorship program motivates me to help people who are in need associated with HD.

Bhairavi
Mentor - Michigan

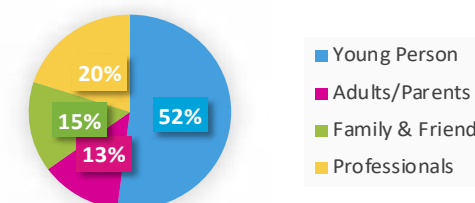


HDYO Impact By the Numbers

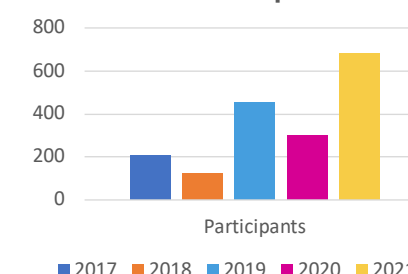
Website, Email & Program Connections



Connections



Event Participation



Educate

HDYO strives to educate and provide resources for the community to support them through every part of their journey with Huntington's Disease. In addition to the robust content on HDYO.org, a series of programs have been developed to bring important topics and concerns directly to young people.



Breaking Down Barriers Series

HD is a complicated disease. We aim to provide educational resources in an easy-to-understand format. We also help young people make connections and communicate with others about their experiences to help others. Breaking Down Barriers was designed to tackle these roadblocks to arm young people and families with this information to help them throughout their journey.

Next Up in 2022...Talking to Children about HD, Access to Health & Research, Being a Young Caregiver, Behind the Scenes Laboratory Tour, Speaking to Children About HD.

An Insight Into Clinical Trials & Drug Development



Participating in Clinical Research



Sponsored By

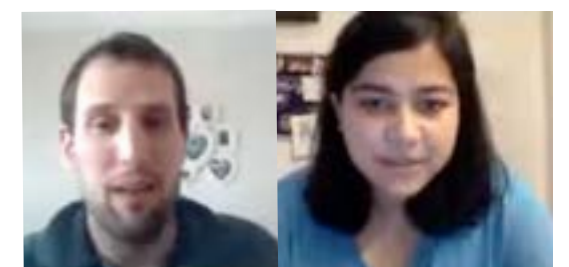
Genentech
A Member of the Roche Group

uniQure

Sage
Therapeutics

Matt's Chats

Featured on social media, Matt's Chats featured interviews with others in the HD community to discuss topics like juvenile onset HD, deciding to do genetic testing, latest in research and more.



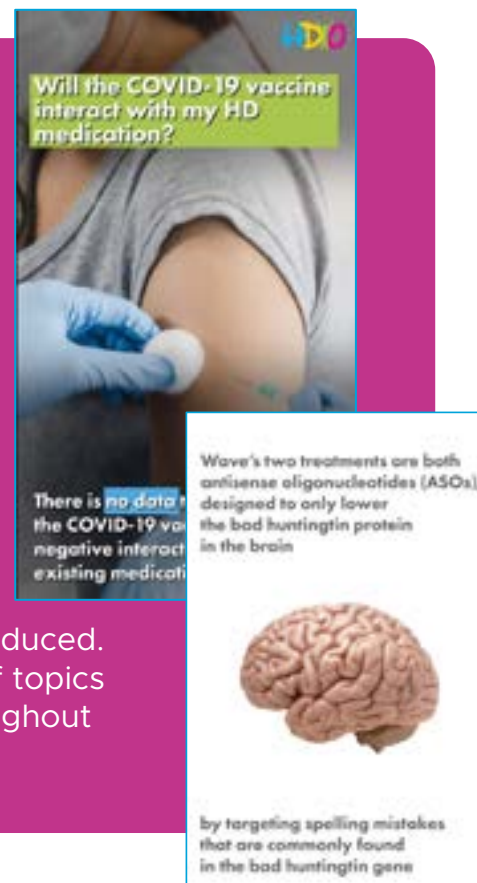
EDUCATE

Research Video Series

Let's face it...most people, especially young people, increasingly look to social media to get their news and updates. HDYO wanted to share the latest about HD research in a format that allows people of all ages to easily access on social media.

HD Buzz creates regular text updates of the latest HD research and has been a major assistance for the HD community. HDYO partnered with HD Buzz to use their research articles and to transform them into two minute-long videos that automatically play on social feeds without needing to click anywhere.

Launched in mid-summer, this series has been well-received with more than 1,000 views and 6 videos produced. We will continue to produce monthly videos on a variety of topics essential to the HD community. Look for more videos throughout 2022!



Special thanks to our sponsors!



Special thanks to our partner!



International Young Adult Congress

The HD community is incredibly diverse. There are vast discrepancies with the level and access of care, support and resources that are available, depending on your country and culture. HDYO has the unique ability to help young people across the world impacted by HD. We aimed to do that physically with our event in 2020. After re-imagining the original event to become virtual, HDYO hosted the first International Congress in March 2021.



This was the FIRST event of its kind because it brought together the HD community across the world in one place, virtually. Attendees heard from different research partners, learned from people in the community, got moving with yoga, dance and exercises, connected with others and walked away feeling inspired. All sessions are featured on YouTube for anyone to access at any time. This essential program was completely free for the community thanks to the generosity of our amazing sponsors. Feedback from young people in addition to pharmaceutical sponsors was extremely positive and 98% of respondents to our survey were excited to join another virtual congress in the next year.

2021 Congress By the Numbers

1,700
BOOTH VISITS

600+
YOUNG PEOPLE & FAMILIES

OVER 29 COUNTRIES

3,000
SESSION VISITS

30+
SPEAKERS

SOCIAL MEDIA PRESENCE

+12,600 FOLLOWERS
+1,600 FOLLOWERS
+2,100 FOLLOWERS

6,000 SUBSCRIBERS
2.6 MILLION VIEWS
2,000 SUBSCRIBERS



HDYO Ambassadors

Our Ambassadors are a group of young people from across the world who are leaders and advocates in the HD community and can help us extend our reach being boots locally on the ground. This group volunteers, raises awareness of HD, advises and fundraises for HDYO. They are truly global coming from US, Canada, South America, Europe, Australia and the Middle East. This group launched after the success of congress in 2021 and meet monthly. They share their experiences and aim to connect the HD community to show they are not alone. They provide support to community members throughout the year including sharing Top Tips to help others, outlining their own journeys, and more. They also keep their fingers on the pulse of the latest in HD and the impacts on young people.

Empower

At HDYO, our aim is to ensure all young people impacted by HD are empowered to help themselves and their families. We encourage them to be their own advocates by sharing their stories and connecting with others in the community.

Clare raised funds by running a half marathon.

Meet Some of Our Ambassadors!

Some Ambassadors Not Photographed



EMPOWER

Huntington's Disease Community Advisory Board (HD-CAB)

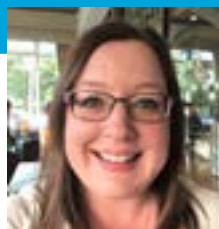
The European Huntington Association (EHA), the International Huntington Association (IHA) and the Huntington's Disease Youth Organization (HDYO) officially launched their new project, HD-CAB. As a coalition of partners, their mission is to represent the voice of the global HD community and provide HD community experience to regulators, industry, researchers and governing bodies.

HD-CAB is an instrument to facilitate patient-oriented research and clinical trials as well as fair processes to make treatment accessible for all patients. For HDYO its so important to have the young persons voice heard as clinical trials look at early symptomatic and pre-symptomatic patients.



We believe that Patient-oriented input is highly needed to meet the needs of the patient community, speed up recruitment and increase retention for all HD clinical trials. We hope that HD-CAB will be successful in incorporating the patient-voice in therapeutic development efforts in Huntington's disease.

Hayley Hubberstey,
HDYO Chair and Member of HD-CAB
Management Team



Partnered Organizations



New Ways of Engagement

There are countless ways to give back and make your voice heard and represented in the HD community. HDYO has enhanced the various ways to give back to HDYO and to the community. These tactics will help diversify our methods of support while enhancing our mission.

Ways to Give

Personal Donations! Supporters can give monthly or monthly and can choose to donate in honor of a loved one.

Donate in Lieu of Gifts! For the next celebration or in memory of a loved one, people can make a donation and choose to send a gift receipt to a loved one.

Start a Facebook Fundraiser! This is the perfect way to celebrate a birthday or milestone while giving back!

Host Your Own Fundraiser! From bake sales to bowling nights, to online parties and quizzes, there are may fun ways to gather to have fun and support HDYO.

Participate on Behalf of HDYO! Make HDYO the beneficiary for your next marathon or competition!

Get Your Workplace Involved! Whether you're an employee or an employer, we'd be happy to chat about making HDYO an approved charity for your workplace giving programs. There are three main ways for employers to support nonprofits: payroll deductions, grant opportunities and matching gifts.

Make HDYO Your Beneficiary! From 401ks to IRAs and other investment accounts, you can make HDYO your beneficiary.



Henley Mermaids Fundraiser

Become A Sponsor Your foundation or company can sponsor our programs that impact the lives of young people and families in the HD community globally. We also offer unique and custom sponsorship opportunities that allow companies and organizations to share their products and services, reach thousands of individuals and enhance their presence in the HD community.

Volunteer! From becoming an Ambassador to joining one of our committees, YOU can help so many others who have been impacted by this disease.

JOIN HD



The HDYO team made great strides in our global Juvenile-onset HD Global Registry. This registry hopes to connect this under-served community and gather history to help support and direct future research for Juvenile onset Huntington's Disease.

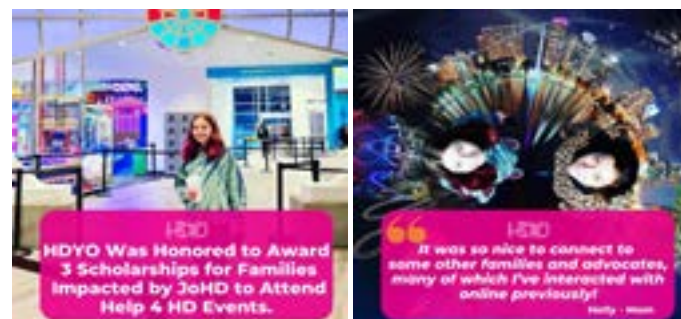
2021 Highlights

- Hired Dr. Rebecca Mason, a dedicated part-time coordinator to manage the registry
- Convened the Scientific Oversight Committee
- Formed the Family Advisory Council
- Pre-registered 32 families in 10 countries
- Presented posters and sessions at 4 conferences to share data and information including HDS Family Day, EHDN, Help 4 HD and Congress.
- Finalized Participant Experience
- Created study documents
- Enhanced registry portal
- Funded 3 families to attend Help 4 HD Conference

Presented At:



Awarded Scholarships:



HDYO Team:



Lauren Byrne
JOIN-HD Chief Investigator



Bonnie Hennig-Trestman
HDYO research co-chair



Rebecca Mason
JOIN-HD coordinator

Scientific Oversight Committee



Martha Nance



Jean-Marc Burgunder



Oliver Quarrell



Leon Dure



Helen Santini



Benjamin Wilfond

What's Next?

The registry will open and active recruitment will begin in the first months of 2022. Any family who has been impacted by juvenile-onset HD is encouraged to register to help connect the community together, identify unmet needs and gaps in care, and to help speed up research for this important community. Once registered, participants will go through a screening call with Dr. Mason and then will receive log in information to complete a series of questionnaires. For more questions and information, email registry@hdyo.org.



Pre-Register Today!

Special thanks to our sponsors!

uniQure



FINANCIALS

THE TEAM

INCOME			
Donations	£	16,996.06	\$ 23,829.66
Grants	£	130,514.18	\$ 179,530.25
	£	147,510.24	\$ 203,359.91

EXPENDITURE			
Grants to HDYO UK	£	92,509.16	\$ 125,000.00
Salaries	£	34,832.98	\$ 47,919.73
Payroll costs	£	242.57	\$ 333.70
Storage	£	112.05	\$ 154.15
Postage & stationery	£	172.13	\$ 236.80
IT costs	£	562.17	\$ 773.38
Telephone	£	171.94	\$ 236.54
Insurance	£	728.63	\$ 1,002.38
Bank charges	£	125.78	\$ 173.04
Office costs	£	599.17	\$ 824.28
Accounts	£	1,987.43	\$ 2,750.00
		£ 132,044.01	\$ 179,403.99
Surplus for Year		£ 15,466.23	\$ 23,955.92

Reserves B/F	\$ 236,886.04
Surplus	\$ 23,955.92
Reserves C/F	\$ 260,841.96
REPRESENTED BY :ASSETS	
Checking Bank Account	\$ 260,341.96
Stocks	\$ 500.00

HDYO Staff



Jenna
Executive Director
jenna@hdyo.org



Jen
Mentorship Project
Coordinator
jen@hdyo.org



Rebecca
ADIN-HD Study
Coordinator
rebecca@hdyo.org



Matt
Founder & Project
Coordinator
matt@hdyo.org

HDYO Board

Executive Committee



Hayley
Works in HD 2 pt



Rudolf
Works in HD 12 pt



Eric
Works in HD 12 pt

Education Committee



Donna
HD Family Member
Works in HD 1 pt



Heather
HD Family Member
Works in HD 4 pt



Ashley
HD Family Member
Works in HD 2.5 pt

Marketing Committee



Clare
HD Family Member
Works in Marketing 20 pt



Jenny
Works in Pharma

Research Committee



Pamela
Works in HD 20 pt



Lauren
HD Family Member
Works in HD 5 pt

Research Volunteer Committee

Misty Daniel
Certified Clinical Research Coordinator,
Scripps Health

Dr. Beth Ann Griffin
Senior Statistician, RAND Center for Causal
Inference

Mustafa Mehkary
PhD Student, University of Toronto

Marina Papoutsis
Biomarker Scientist, IXICO plc, Honorary
senior research fellow, UCL

Marketing Volunteer Committee

Emily Hadley
Retail Buyer, World of Sweets

Education Volunteer Committee

Angela Abell
HDYO Ambassador, Impacted by HD

Erika Brockhoff
Prenatal Genetic Counselor, Impacted by HD

Marc Osborn
High School Teacher, Impacted by HD

Bhairavi Srinageshwar
Post-Doc Research Associate

Brittany Stowers
Student Studying Neuroscience and
Psychology, Impacted by HD

Dr. Emma Yhnell
HD Researcher, Cardiff University

Jessi Way
Masters of Science, Licensed Professional
Counselor, Impacted by HD



**Join the Celebration in
2022!**



@HDYouthOrg



@HDYOFeed



@HDYOFeed



@HDYO



@HDYOFeed



HDYO.ORG